

111TH CONGRESS
1ST SESSION

S. 792

To amend the Public Health Service Act to improve the National Program of Cancer Registries by expanding data collection and allowing data sharing for public health objectives, while preserving the confidentiality of patients, and for other purposes.

IN THE SENATE OF THE UNITED STATES

APRIL 2, 2009

Mr. SANDERS introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

A BILL

To amend the Public Health Service Act to improve the National Program of Cancer Registries by expanding data collection and allowing data sharing for public health objectives, while preserving the confidentiality of patients, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Improvement of the
5 National Program of Cancer Registries Act”.

6 **SEC. 2. FINDINGS AND PURPOSE.**

7 (a) FINDINGS.—Congress finds as follows:

1 (1) The National Program of Cancer Registries,
2 established in 1992 by the Cancer Registries
3 Amendment Act (Public Law 102–515; 106 Stat.
4 3372), has enabled each of the 50 States to main-
5 tain a functioning cancer registry.

6 (2) Over the past 15 years, the Centers for Dis-
7 ease Control and Prevention has enhanced central
8 cancer registries and helped to establish standards
9 for quality and completeness of such registries.

10 (3) The statewide, population-based cancer reg-
11 istries collect information on cancer incidence and
12 mortality rates, which may be used for identifying
13 cancer patterns and trends and for directing cancer
14 control interventions.

15 (4) The States rely on electronic records, espe-
16 cially electronic laboratory records, for the majority
17 of data collection for the cancer registries.

18 (5) The States do not have adequate resources
19 to access all of the records of physicians, hospitals,
20 outpatient clinics, nursing homes, and other agencies
21 providing services to cancer patients that would as-
22 sist in identifying characteristics of each patient and
23 treatment of the cancer.

24 (6) Laboratories do not systematically collect or
25 record essential data, including information on the

1 occupation, socioeconomic status, or treatments of,
2 or environmental factors affecting, cancer patients,
3 and thus cancer registries, which depend in part
4 upon records of laboratories, do not have essential
5 data that would help determine causes or contribu-
6 tory causes of cancers.

7 (7) The National Program of Cancer Registries
8 has established standards for collecting information
9 but has not established standards that allow data ex-
10 change with other disease registries.

11 (8) Information collected by cancer registries
12 must be exchanged with other disease registries in a
13 confidential and secure manner in order to prevent
14 information about patients from being used for pur-
15 poses other than medical treatment, medical re-
16 search, or public health.

17 (b) PURPOSE.—The purpose of this Act is to improve
18 the National Program of Cancer Registries by expanding
19 the data elements collected, enhancing the quality of infor-
20 mation collected, and collecting data such that the Na-
21 tional Program of Cancer Registries preserves the con-
22 fidentiality of patients while allowing data sharing for
23 public health objectives.

1 **SEC. 3. AMENDMENTS TO THE NATIONAL PROGRAM OF**
 2 **CANCER REGISTRIES.**

3 (a) ENHANCING DATA COLLECTION.—Section
 4 399B(a)(1) of title III of the Public Health Service Act
 5 (42 U.S.C. 280e(a)(1)) is amended—

6 (1) in the matter preceding subparagraph (A),
 7 by striking “registries to collect, for each condition
 8 specified in paragraph (2)(A), data concerning”, and
 9 inserting “cancer registries in order to collect, for
 10 each form of in-situ and invasive cancer (with the
 11 exception of basal cell and squamous cell carcinoma
 12 of the skin), data in a standardized manner con-
 13 cerning”;

14 (2) by striking subparagraph (B) and inserting
 15 the following:

16 “(B) information on the industrial or occu-
 17 pational history of adult individuals with the
 18 cancers, using the Federal Standard Occupa-
 19 tional Classification system;”;

20 (3) in subparagraph (D), by striking “and”
 21 after the semicolon;

22 (4) by inserting after subparagraph (D) the fol-
 23 lowing:

24 “(E) the highest level of education attained
 25 by adult individuals with the cancers;

1 “(F) sources of payment by individuals
 2 with cancer for costs associated with cancer di-
 3 agnosis and treatment;

4 “(G) history of alcohol and tobacco use by
 5 individuals with cancer; and”; and

6 (5) by redesignating subparagraph (E) as sub-
 7 paragraph (H).

8 (b) ESTABLISHING DATA COLLECTION STAND-
 9 ARDS.—Section 399B of title III of the Public Health
 10 Service Act (42 U.S.C. 280e) is amended by inserting at
 11 the end the following:

12 “(f) DATA COLLECTION STANDARDS.—

13 “(1) IN GENERAL.—The Secretary, acting
 14 through the Director of the Centers for Disease
 15 Control and Prevention, shall—

16 “(A) develop standards for collection of
 17 each data element for the State cancer reg-
 18 istries assisted under this section;

19 “(B) develop inter-operability and security
 20 standards for data exchange and integration be-
 21 tween—

22 “(i) the cancer registries of 2 or more
 23 States; and

24 “(ii) any cancer registry and another
 25 Federal registry for non-cancer diseases

1 that contains data concerning individual
2 patients; and

3 “(C) provide a basic electronic collection
4 tool, to facilitate standardized data collection,
5 available to each State to use for cancer reg-
6 istries.

7 “(2) ASSURANCES.—Each applicant, prior to
8 receiving Federal funds under the Improvement of
9 the National Program of Cancer Registries Act,
10 shall provide assurances satisfactory to the Secretary
11 that the applicant will comply with standards devel-
12 oped under paragraph (1).

13 “(3) COORDINATION WITH OTHER FEDERAL
14 PROGRAMS.—To promote the greatest possible effi-
15 ciency and effectiveness in the collection of data for
16 federally-supported cancer registries, the Secretary
17 shall facilitate appropriate coordination of the Na-
18 tional Program of Cancer Registries under this part
19 with other federally-supported registry programs, in-
20 cluding infectious disease registries, environmental
21 disease registries, and other non-cancer, chronic dis-
22 ease registries.”.

1 **SEC. 4. AUTHORIZATION.**

2 To carry out this Act, there are authorized to be ap-
3 propriated \$100,000,000 for each of the fiscal years 2010,
4 2011, 2012, and 2013.

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